

Surviving Cancer: From Oncology to Primary Care

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Summary

As the number of people surviving cancer continues to increase, issues of survivorship have become a growing focus for health care providers and patients. Currently, there is a lack of standardized guidelines on what survivorship care should entail. Models are being developed and research conducted at various cancer centers across the country to better address cancer survivorship.

Key Points

- Cancer survivorship issues will continue to grow in significance for patients, clinicians, health care systems, and payers.
- Lack of guidelines and research create great challenges in providing survivorship care.
- An Institute of Medicine report provides strategies for addressing survivorship issues, which are now being implemented by various cancer centers.
- Models of care are being tested to address how to provide survivor care effectively.

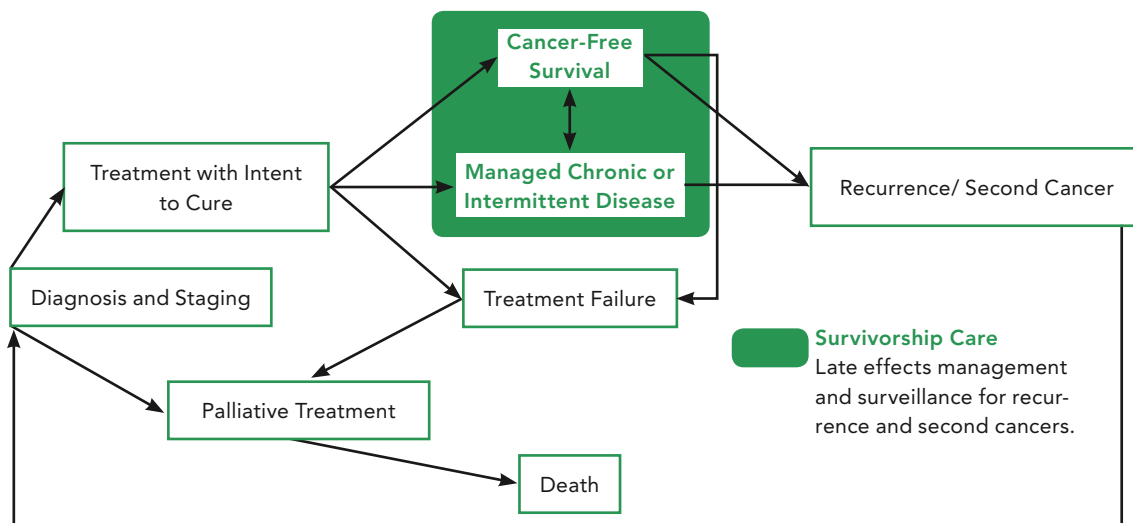
THERE IS NOW A GROWING FOCUS ON cancer survivorship for many reasons. There is a rapidly growing population of cancer survivors due to advances in diagnosis and treatment. It is estimated that there are at least 11 million cancer survivors in the United States today.¹ As the population continues to age, cancer incidence and survival rates are predicted to continue climbing. Sixty two percent of adults with cancer today can expect to be alive in five years.¹ Greater than 75 percent of children with cancer can expect to be alive in 10 years.¹ There is a greater emphasis on patient-centered issues of quantity and quality of life by the medical community. There also are increasing expectations by patients for good quality of life after treatment.

In the past five years, there has been a lot of national attention paid to cancer survivorship. Much of the credit goes to advocacy groups. The National Cancer Institute, Centers for Disease Control, and the National Coalition for Cancer Survivors all have contributed to making survivorship a national issue. In 2005, the Institute of Medicine (IOM) issued a report on recommendations for meeting the needs of cancer survivors.² According to this report, all patients should have a survivorship care plan

implemented. Bridges should be built between oncology and primary care because there has been a lack of information transfer between both areas. The report also noted that models of care should be developed and tested. Currently, there are no national guidelines for cancer survivorship care. This is a real dilemma and guidelines should be developed. The report also called for institution of quality assurance, strengthening of professional education, making better use of psychosocial and community support services, and addressing employment and insurance issues.

According to the National Coalition for Cancer Survivorship, cancer survivors are all living persons who have ever received a diagnosis of cancer, along with family members, friends, and caregivers. A programmatic definition of survivorship is a period in which patients treated with curative intent have completed their initial therapy and require follow-up care.³ This period lasts until there is a cancer recurrence, a second cancer, or death, and may include some ongoing treatment, such as adjuvant hormonal therapy.² Exhibit 1 shows a cancer care trajectory developed by the IOM.² Post treatment care includes various domains of care: physical/medical, psychological, social, existential and spiritual,

Exhibit 1: Cancer Care Trajectory



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and informational. The physical and medical area may include organ toxicity and second cancers. Fear of recurrence, anxiety, and depression are all psychological areas of concern. Socially, the patient may have relationship, economic, and education issues. There may be existential or spiritual concerns such as loss or deepened meaning in life. Patients also need ongoing, comprehensive information. With various types of cancer, there are documented physical and psychosocial sequelae that can occur post treatment (Exhibit 2).⁴

When models of care for cancer survivors are developed, all of the domains and issues in Exhibit 3 should be considered. The essential components of survivorship care include surveillance for recurrence; prevention and detection of new cancers; management of consequences of cancer and treatment; coordination between specialists and primary care providers; assistance with transition to wellness; and promotion of healthy behaviors.

Few guidelines are available on recurrence surveillance. There is a lack of evidence and consensus on follow-up. Surveillance can lead to patient psychological distress. Although surveillance seems like a good thing, there is little evidence of improved outcomes and it is expensive. In general, cancer recurrence is more commonly detected by patient complaint of symptoms. Surveillance is justified for the identification of disease that can be cured or survival prolonged. Guidelines for this process can eliminate unnecessary and harmful care, and can facilitate delivery of necessary care.

The usual practice is for most patients to have follow-up by oncologists. The duration of follow-up is

variable because of the lack of national guidelines. Locally developed follow-up guidelines are limited. Follow-up care typically focuses on surveillance for recurrence and does not address other issues. There is typically a limited transfer of knowledge and information from oncologists to primary care providers.

Long-term follow-up programs are growing. This is important for several reasons. There is a need to determine the best care for the large number of individuals in follow-up. There is a need for greater understanding of the consequences of cancer and its treatment. A focus on interventions to eliminate or reduce sequelae is needed. Lastly, a follow-up care setting with continuity care can be a platform for research. Also in this setting, providers can focus on education and training in survivorship for other health care providers.

Children with cancer tend to get treatment at large specialty centers, so pediatric follow-up programs have been in existence for 15 to 20 years. There are more than 200 long-term follow-up clinics in this country. Typically, a patient will be referred to a follow-up clinic at two years post-treatment. Most follow-up clinics are freestanding, multidisciplinary, and not disease specific. They provide risk-based survivor care.

There are some adult care programs that provide short-term post-treatment care, but these are relatively new. Many are breast-cancer specific. There also are programs that use a consultative model where the patient has a one-time visit with a survivorship specialist. The focus is on a medical summary and systematic plan development for surveillance. There are ongoing care models that focus on

Exhibit 2: Consequences of Cancer Treatment by Cancer and Domain

Cancer	Physical Sequelae	Psychosocial Sequelae
Breast	Menopausal symptoms Osteoporosis Lymphedema, Weight gain Cognitive Loss	Anxiety Sexuality Body Image
Colon and rectal	Colostomy, Anal incontinence Radiation proctitis Sexual dysfunction	2nd to physical sequelae
Prostate	Sexual dysfunction Urinary incontinence Radiation proctitis	Anxiety, Depression Others 2nd to physiologic alterations
Lung	Reduced lung function Renal impairment, Neuropathy, Pain, Cognitive loss	Dependence on others due to dyspnea and cognitive loss; Anxiety, fear of recurrence
Hodgkin's Disease	Fatigue, Hypothyroidism Heart failure Reduced lung function Infertility, Weight gain Sexual dysfunction	Marital difficulties Sexual problems
Leukemias, NHL	Fatigue Heart failure Hepatitis Infertility, Sexual dysfunction	Marital difficulties Sexual and Vocational problems
GYN cancers	Menopausal symptoms Sexual dysfunction Urinary frequency Vaginal stenosis Neuropathy	Fear of recurrence Others 2nd to physiologic alterations

Reference: 4

extending the care continuum post cancer treatment. Many times these ongoing care practitioners are imbedded with the treatment team. There also are multidisciplinary, long-term follow-up programs that follow the pediatric model.

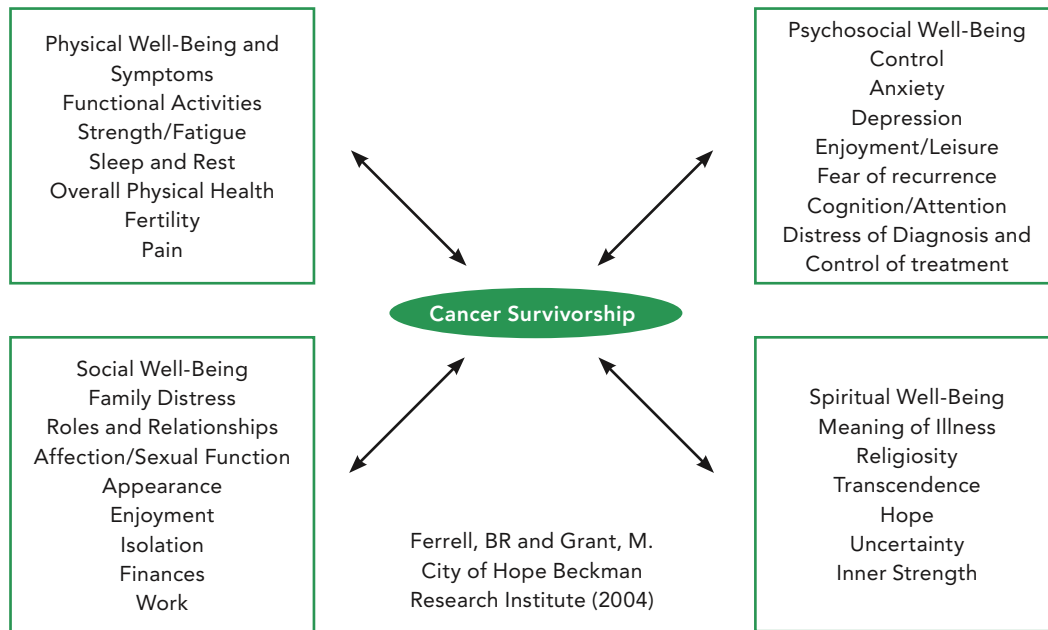
The majority of the pediatric and adult care models are seen in academic institutions. Unfortunately, most cancer survivors receive their care in a community setting and no model currently exists for oncology follow-up in this setting. A shared-care model like chronic disease management is the model for the community setting to emulate. Studies demonstrate improved patient outcomes and enhanced management of chronic disease. Studies suggest that a shared-care model is applicable to care of cancer survivors.

A shared-care model is care shared by two or more clinicians of different specialties. There is a common understanding of expected components of care and

respective roles. There also is clear communication between the cancer specialist and primary care physician. It is generally risk-stratified in approach. Low risk for recurrence individuals is transferred for care from the oncologist to general practitioner earlier than moderate or high-risk individuals. Moderate-risk individuals will have joint follow-up between the oncology team and primary care. They are transitioned to primary care later than low-risk individuals. High-risk individuals stay under the care of an oncologist while their non-oncology needs are taken care of by primary care.

There are several challenges to a shared-care model. The currently fragmented health care system causes difficulty in maintaining communication. Other challenges include lack of evidence-based guidelines; lack of training and education about survivor issues in oncology and primary

Exhibit 3: Quality of Life Model Applied to Cancer Survivors



care; lack of awareness of late effects from cancer treatment; lack of awareness of interventions for late effects; and lack of insurance coverage for survivorship services.⁵

According to the IOM report, patients completing cancer treatment should be provided with a comprehensive care plan that is clearly and effectively explained, written by principal providers of oncology treatment, and reimbursable by third-party payers of health care.² A care plan is a way to build a bridge for transitioning patients from oncology care to primary care. A written care plan helps with care coordination, patient-physician communication, physician-physician communication, and efficiency. Exhibit 4 outlines the components of a survivorship care plan. This plan should include a summary of the treatment the patients have received and a plan for ongoing care. Sample survivorship care plans are available from the American Society of Clinical Oncology (www.asco.org) and Oncolink (www.oncolink.com). Oncolink is a site for patients to obtain survivorship information.

There are some challenges to creating care plans. Some of these are barriers previously discussed. The barriers include a lack of evidence-based follow-up guidelines, a lack of research on which patients need a plan and when they should be completed, and a need for cultural change.⁶

Memorial Sloan Kettering Cancer Center (MSKCC) has developed a cancer survivorship program. Some of the goals of this program are

survivorship research and services for all age groups; development and evaluation of models of care; development of new clinical programs addressing greatest need; expansion of the survivorship research community; and development and dissemination of information. The survivorship model for this

Exhibit 4: Elements of Survivorship Care Plan:

Treatment Summary

- Cancer type
- Tumor characteristics
 - site, pathology, stage, and grade
- Treatments received
 - Surgical procedure,
 - Chemo/bio/hormonal therapy-agents, regimen, dose, clinical trials, dates
 - Transplant
 - Radiation therapy-type, site, dose, dates
- Care provider and institution contact information

Ongoing Care Plan

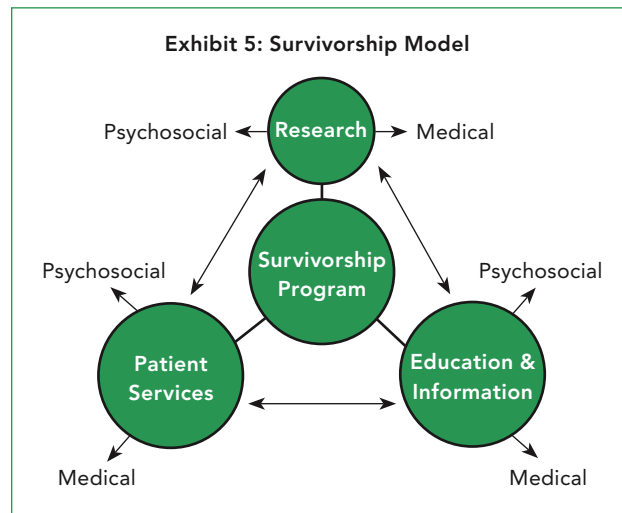
- Timing and content of surveillance
- Monitoring potential consequences of treatment
- Recommendations for preventive practices and maintaining health and well-being
 - Cancer screening
 - Smoking cessation
 - Nutrition, diet, weight control
 - Exercise
 - Sunscreen
 - Osteoporosis prevention
 - Immunizations
 - Psychosocial concerns
 - Identification of providers

Reference: 2

program is shown in Exhibit 5. A pediatric long-term follow-up program and a post-treatment resource program were already in existence for about 15 years. Program staff, a steering committee, and long-term follow-up clinic leaders do oversight and management of the cancer survivorship program. The efforts were guided by clinical and research pilot team leaders, ad hoc work groups, and a metrics committee. A survivorship database was developed for research purposes.

The patient services that were put into place included new services, expanded current services, and a communication system between patients and providers. Some new services that were needed included a clinic for adult survivors of pediatric cancer, a sexual health program, and reproductive medicine and fertility preservation consultation. The sexual health program idea came from patient focus groups, which identified this as an unmet need. More availability of onsite specialists for fertility consultation is the most recent addition to the program. Existing services such as nutrition and physical rehabilitation were opened to survivors.

In this shared-care model, nurse practitioners (NP) are the primary oncology provider. They communicate on an ongoing basis with the community physician. A risk-based approach is used where the transfer from oncologist to NP care begins when patients have recovered from the immediate effects of treatment and the risk of recurrence is reduced (Exhibit 6). Patients are then transferred to primary care when feasible. The time frame for care transition varies for each type of cancer. For example, patients with prostate cancer go to NP care one year after surgery and then are transferred to primary care at five years. Standards for follow-up care had to be developed for this program (Exhibit 7).



The NP works within a disease management team and care is provided in disease-specific clinics. For example, the breast cancer survivors are cared for in a breast cancer specific clinic that provides active treatment and survivorship care. The focus of the survivorship clinic visits includes surveillance for recurrence of the primary cancer; evaluation and treatment of medical and psychosocial consequences of treatment; screening for second cancers; patient education about survivorship issues and availability of community resources; health promotion, including smoking cessation and sexual health services; and communication with community physicians. The clinics in operation at MCKSS are urology - prostate, renal, and bladder surgery; prostate radiation; thoracic surgery; breast medicine; breast surgery; and colorectal surgery.

In terms of analyzing outcomes of the MCKSS clinics, patient and provider satisfaction has been high. Sustainability and success in facilitating shared-care

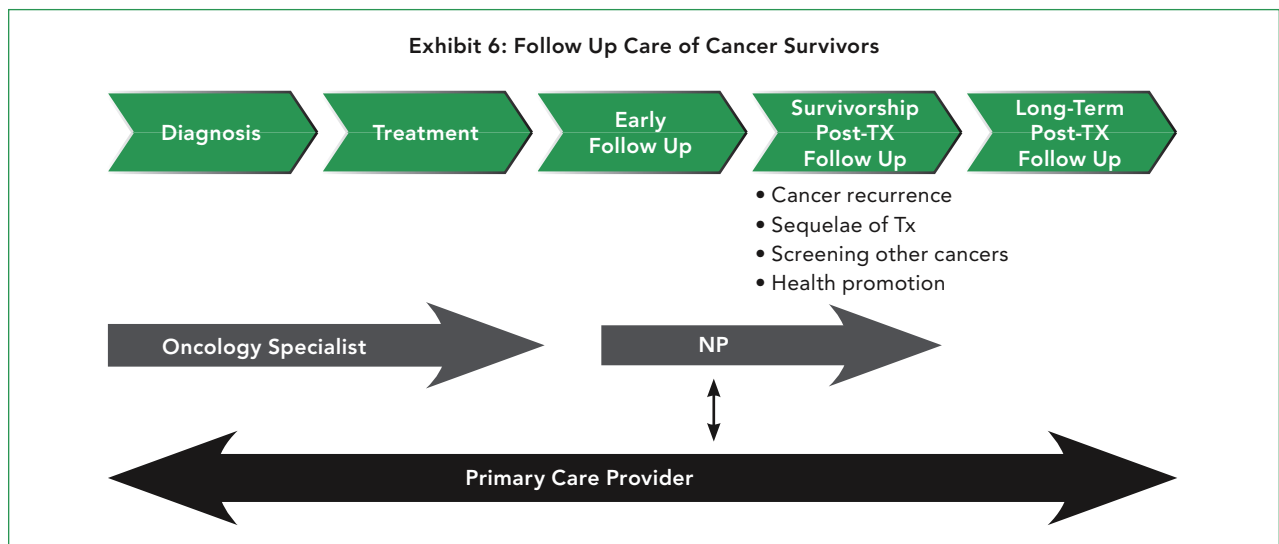


Exhibit 7: Survivorship Standard Follow-up Care

Service	Cancer Type	Interval	Visit	Testing	Stage/Primary Provider
Thoracic	Lung	Year 1	Every 6 months	CT scan w/ contrast	Stage I-II/Surgeon
		Year 2	Every 6 months	CT scan w/ contrast	Stage I-II/Nurse Practitioner
		= Year 3	Annual	CT scan w/out contrast	Year 1- Surgeon
Urology	Prostate	Year 1	Every 6 months	PSA every 6 months	= Year 1- Nurse Practitioner
		Year 2	Every 6 months	DRE and PSA every 6 months	
		Year 3-5	Annual	DRE Annual/ PSA every 6 months	
		>Year 5	Annual	Annual PSA/DRE	
Colorectal	Colon	Year 1-2	Every 4 months	CEA/scope depending on tumor site and CT scan depending on stage	Year 1- Surgeon Year 2- Nurse Practitioner
		Year 3-5	Every 6 months	CEA/scope depending on tumor site and CT scan depending on stage	Nurse Practitioner
		Year > 5	Annual	CEA	Nurse Practitioner
	Rectal	Year 1-2	Every 4 months	CEA/Scope	Surgeon
		Year 3-5	Every 6 months	CEA/Scope	Surgeon/Year 5 Nurse Practitioner
		Year = 5	Annual	CEA	Nurse Practitioner
Breast	Breast Surgery	Year 1-2	Every 6 months	Clinical breast exam, Annual mammogram	Surgeon
		> Year 2	Annual	Clinical breast exam, Annual mammogram	Nurse Practitioner
	Breast Medicine	Year 1-2	Every 3-4 months	Clinical breast exam, Annual mammogram	Medical Oncologist
		Year 3-5	Every 6 months	Clinical breast exam, Annual mammogram	Medical Oncologist
		> 5 years	Annual	Clinical breast exam, Annual mammogram	Nurse Practitioner

also has been demonstrated. These programs were started with philanthropy money but have since been moved under hospital operations. There has been growing acceptance by physicians with support of medicine, surgery, and radiation department chairs. There also is a growing medical and psychosocial research community at Memorial Sloan Kettering. Additionally, philanthropy money has provided continued support. The physical rehabilitation center was expanded with this funding.

Some of the challenges for Memorial Sloan Kettering are sustainability of the programs, finding different solutions for different survivor populations, reimbursement for services, lack of adult follow-up guidelines, and limited federal research funding.

Conclusion

Cancer survivorship issues will continue to grow in significance for patients, clinicians, health care systems, and payers. Lack of guidelines and research create great challenges in responding to survivorship

needs. The implementation of strategies recommended by the IOM report are underway with models of care being tested to address how to provide effective survivorship care. **JMCM**

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